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ORIGINAL ARTICLE

# A Study to Assess the Quality of Life (QOL) Among Parents of Children with Acute Lymphoblastic Leukemia (ALL) Attending Oncology Out Patient Department (OPD) In Selected Hospital of Kolkata, West Bengal, India

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## ABSTRACT

**Introduction:** Acute Lymphoblastic Leukemia (ALL) is the most common childhood cancer. The leukemia affects not only the quality of life (QOL) of children but also their caregivers. This study aimed to identify the Quality of Life of parents of children with ALL and to find out the association between QOL of parents of children with ALL and the selected demographic variables. **Methods:** A descriptive study was conducted to assess the QOL among parents of children with ALL. Non-probability purposive sampling technique was followed to select 70 parents of children with ALL attending oncology Outpatient Department in selected hospitals of Kolkata, West Bengal. Semi-structured interview was conducted and the 'Adult Carer Quality of Life (ACQOL)', the standardized questionnaire was used to assess the quality of life. **Results:** The study findings revealed that majority (71.43%) of the parents were mother, maximum (77.14%) parents were belonged to the 30-40 years of age group, majority (42.86%) of the parents spent more than 60 hours per week for caring. It was found that majority of the clients 48 (68.57%) had perceived their quality of life as 'Mid-range'. There was a significant association between QOL and monthly family income and time (in hours) spent for caring per week. **Conclusion:** The study was believed to be a helpful guide for future study on assessment of Quality of Life of any other caregivers in a large sample for better generalization.

**Keywords:** Parents, Acute Lymphoblastic Leukemia (ALL), Quality of life

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## INTRODUCTION

Acute lymphoblastic leukemia (ALL) is very much prevalent among children (1). ALL affects about 876,000 peoples in 2015 and resulted in about 111,000 deaths globally (2, 3). Occurrence of ALL is in between the age group of 2-5. The increase in survival rates among children has been reported from 10% in the 1960s to 90% in 2015, it is 25% among childhood cancers and approximately 75% of childhood leukemia (4). The survival rate has improved from virtually zero to the current overall approximately 80% with the initiation of modern chemotherapy and radiotherapy (in 1950s), (5,6,7). Guru et al., 2018 mentioned appropriate risk stratification of ALL patients with adverse prognostic factors and treatment modification India and found the outcome is similar as reported in the western countries (8).

Noteworthy advancement has been achieved with regards to treatment of acute lymphoblastic leukemia (which constitute 75–80% of childhood acute leukemia) with 5-year overall survival rate reaching 90% in the high-income countries. There is limited information pertaining to childhood cancer survival tendencies from India. However, there is published evidence that there has been progress in the outcomes of childhood ALL, in India although the magnitude of progress has been more modest. 25,000 Indian children diagnosed with acute lymphoblastic leukemia every year (9).

The family of the ALL patient plays an important part in the early diagnosis of cancer in children and adolescents. ALL is the second leading cause of death among children aged 5 to 14 years in spite of the present advances in treatments (10). Deaths due to ALL were significant and ranged from 2%-13% during induction phase and 4%-24% during treatment (11).

Children with chronic diseases require high level of caring which alter the physical, psychological health, social wellbeing of parents. A diseased child's family adjusts to several aspects of life to suit the needs. Caring for such children can be a physically and mentally tasking job, depending on the type of disease resulting in compromised quality of life (QOL). Even the carers need help to deal with the physical, mental and emotional stress they bear while caring for their loved one (12).

The primary caregivers among family members need and demand are often overlooked and neglected as the care and treatment focused on the patient only. The caregivers crucial job role is well recognized by all but their personal burden is overlooked. Family members, who are working as caregivers for the patient in the reality, experience a number of stress factors. The lifestyle is affected by malignancy includes nursing care, communication, emotional conflicts and financial concerns (13).

Diminishing of health-related quality of life has been noticed among parents of children with chronic diseases like congenital heart disease, pervasive developmental disorders, cerebral palsy, sickle cell anemia and cancer (14). A variety of factors and coping strategies influences the Qualities of life of the parents (15).

In India, leukemia is the most predominant infantile cancer which relative between 25% and 40% in proportion (16). ALL is about 60% to 85% among all leukemia. Yearly occurrence of ALL is about 9-10 cases per 100,000 populations in children (17). The diagnosis and treatment procedure of ALL appears to be different in India in comparison to other developed countries. This is due to the poor prognosis of leukemia (18, 19).

Another alarming fact is that only one in 10 of the childhood cancer cases receive appropriate treatment. Due to this remedy rates for childhood cancers like lymphoma and leukemia in India, is still extremely low at around 30% compared to over 80% in the developed countries (20).

According to the concept of World Health Organization (WHO), "Quality of life is defined as an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (21). Health, jobs, housing, education, society, aspects of culture, values, norms, spirituality are also key domains of overall QOL contributing complexity of its measurement (22).

For precise diagnosis along with the sustenance of an effective intervention is necessary for improvement of QOL valuation. This is an important tool for health care professionals. Though self-report is the best method to evaluate personal experiences, the caregiver's perception must not be disregarded as it is vital part of QOL in decision-making (23).

Many studies indicate that the number of leukemic children is increasing and the quality of life of the parents is also affected due to various factors. Based on these literatures and their statistical analysis researcher felt that the assessment of QOL of parents with children suffering from Acute Lymphoblastic Leukemia is important in the present situation. Thus the purpose of this study was to measure the Quality of Life of parents with children suffering from Acute Lymphoblastic Leukemia and detect the association between sample characteristics and Quality of Life.

## MATERIALS AND METHODS

A descriptive survey approach is implemented to collect data from parents of children diagnosed with ALL. In the present study samples included the parents of children diagnosed with ALL, in selected hospitals. A purposive sampling method was applied to collect data. A total of 70 parents of children diagnosed with ALL were selected as sample that fulfilled the following inclusion and exclusion criteria. The inclusion criteria were parents of children diagnosed with ALL, willing to participate, available during study period and able to follow instruction. The exclusion criteria was parents that is unable to read and write English, Bengali and Hindi.

The parents were interviewed face to face. Demographic characteristics were assessed by using semi structured interview schedule and quality of life was assessed by using standardized questionnaire items for Quality of Life Assessment Scale (24). Before data collection the tools were given to experts for validation and linguistic modification of the tool.

### Research tools

The following tools were used for the collecting data:

Tool- I: Demographic proforma for the parents of children diagnosed with ALL

The tool is developed to collect demographic data of the parents. The tool describes the demographic characteristics of the parents of children diagnosed with ALL including age, gender, marital status, residential place, education, occupation, type of family, health related problem, any exposure of all treatment, per capita income, hours spend in caring etc.

Tool-II: Standardized questionnaire for quality of life of parents of children diagnosed with ALL.

The tool is a standardized questionnaire items for Quality of Life assessment based on Adult Carer Quality of Life Questionnaire (AC-QoL) (24). AC-QoL is a simple 40-item based instrument which measures QOL in eight separate domains: caring choice; support for caring; caring stress; personal growth; money matters; ability to care; sense of value; and carers satisfaction (24). Score ranged between 0 to 120 with higher scores representing greater QOL. The questionnaire was used to assess QOL at the time of administration (25).

In this present study researcher use that tool in unchanged form. No modification was done. Only linguistic translation was done from English to Bengali and re-translated from Bengali to English.

## Ethical consideration

The study protocol was approved by the Ethical Committee of R.G.Kar Medical College and Hospital, Kolkata, India (vide memo no. RKC/ethics/34 dated 8th May 2018).

Prior to the translation and data collection, permission was obtained to use the ACQOL questionnaire directly from Saul Becker by email. Informed consent was taken from each willing client prior to data collection and ensured that the data was kept confidential within researcher and was used only for research purpose.

## Data analysis

The analysis of the data was based on objectives by using descriptive and inferential statistics. The subjects characteristics were presented as frequency and percentage distribution. Quality of life were assessed by mean, median, mean percentage, standard deviation. Associations of Quality of life with selected demographic variables were analysed by chi square test of association.

## RESULTS

## Sample characteristics

Findings of the individuals that participated in this study related to the demographic data reveal that majority 54 (77.14 %) of the parents belonged to the age group of 30-40 years and the mothers were 50 (71.43%). Majority 67 (95.71%) were married and 37 (52.86%) live in urban area. Majority 37 (52.86) of the parent's monthly family income was between rupees 20001-40000 and maximum of them have less than or equal to 4 family members. Among the participants 61 (87.14 %) parents did complain about any health-related issue and maximum 65 (92.86%) parents were free from any exposure to ALL. Majority of the parents i.e. 30 (42.86%) spent more than 60 hours per week for caring and maximum 46 (65.71%) parents have been carer for less than 3 years for their sick child. (Table I). Apart from these Fig.1 and Fig. 2 show that majority 26 (37.14%) of the parents had completed education up to graduate and maximum 38 (54.29%) of the parents were homemaker.

## QOL Assessment

QOL assessment was done with the help of ACQOL questionnaire and the results showed that majority of the clients 48 (68.57%) had perceived their quality of life as 'Mid-range' (Table II). According to obtained score in the ACQOL questionnaire analysis of QOL shows that parents between age group of less than 30 years had low quality of life than other age group and majority of the father and mother perceived their quality of life as mid range (60% and 72% respectively). Majority of service-oriented parents 8 (88.89%) had mid-range quality of life, parents of low-income group have more percentage of low quality of life than others and majority of parents

**Table I: Frequency and percentage distribution of the sample according to their demographic variables (n=70)**

| Demographic variable | Frequency | Percentage % |
|---|---|---|
| Age in years | | |
| <30 years | 8 | 11.43 |
| 30-40 years | 54 | 77.14 |
| > 40 years | 8 | 11.43 |
| Gender | | |
| Father | 20 | 28.57 |
| Mother | 50 | 71.43 |
| Marital status | | |
| Married | 67 | 95.71 |
| Unmarried | 0 | 0.00 |
| Widow / Widower | 3 | 4.29 |
| Residential place | | |
| Urban | 37 | 52.86 |
| Semi-urban | 29 | 41.43 |
| Rural | 4 | 5.71 |
| No of family member | | |
| ≤ 4 | 55 | 78.57 |
| > 4 | 15 | 21.43 |
| Monthly family income (Rupees/month) | | |
| ≤ 20000 | 10 | 14.28 |
| 20001-40000 | 37 | 52.86 |
| > 40000 | 23 | 32.86 |
| Health related problem | | |
| Yes | 9 | 12.86 |
| No | 61 | 87.14 |
| Any exposure of ALL treatment | | |
| Yes | 5 | 7.14 |
| No | 65 | 92.86 |
| How many hours do you spend for caring per week | | |
| ≤ 30 hrs | 12 | 17.14 |
| 31-60 hrs | 28 | 40 |
| > 60 hrs | 30 | 42.86 |
| How long have you been a carer for | | |
| 0 to 3 | 46 | 65.71 |
| 4 to 6 | 18 | 25.71 |
| >6 | 6 | 8.58 |

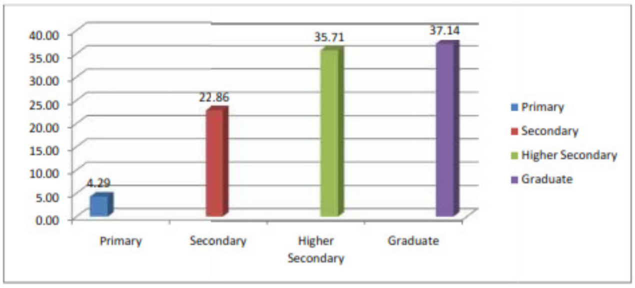

**Figure 1: Distribution of parents' education status**

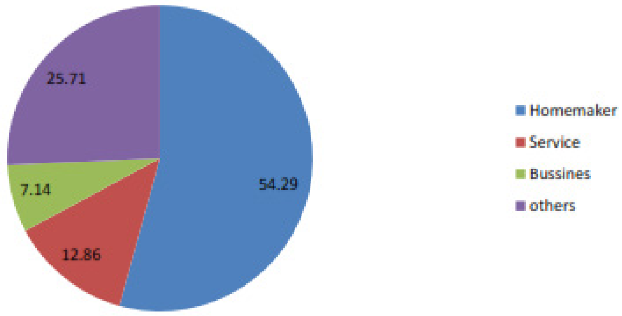

**Figure 2: Distribution of parents' occupation**

**Table II: Frequency and Percentage distribution of the sample according to their Quality of Life (n=70)**

| Quality of life | Frequency | Percentage % |
|---|---|---|
| Low (<40) | 16 | 22.86 |
| Mid-range (40 - 80) | 48 | 68.57 |
| High (>80) | 6 | 8.57 |

Maximum possible Score – 120
Minimum possible Score – 0

with health-related problem perceived their quality of life as low (66.67%). Longer time spent on care giving per week results in lower QOL among parents and parents with longer duration as a carer have low quality of life than others (Table III).

Taking into consideration the domains of ACQOL questionnaire, the present study results revealed that the quality of life was highest in the sense of value domain with a mean percentage of 90.3 and lowest in ability to care (mean percentage of 24.7) domain (Table IV).

**Table IV: Domain wise mean and mean percentage of quality life score (n=70)**

| Domain of Quality of life | Mean | Mean Percentage % |
|---|---|---|
| Support for care | 3.8 | 25.4 |
| Caring choice | 8 | 53.2 |
| Caring stress | 8 | 53.2 |
| Money matters | 3.8 | 25.4 |
| Personal growth | 4.6 | 31 |
| Sense of value | 13.5 | 90.3 |
| Ability to care | 3.7 | 24.7 |
| Carer satisfaction | 9.4 | 62.6 |

## Association between quality of life of parents of children with ALL and selected demographic characteristics

Chi square test of association was done here as statistical analysis. The results found no significant association between quality of life and demographic variable except

**Table III: Perceived quality of life of parents according to their Age, Gender, Monthly family income, Health related problem , Spending weekly time for caring and Duration for caring (n=70)**

| Demographic variable | Low |  | Mid-range |  | High |  | Total |
|---|---|---|---|---|---|---|---|
|  | Frequency | Percentage % | Frequency | Percentage % | Frequency | Percentage % |  |
| Age |  |  |  |  |  |  |  |
| <30 yrs. | 4 | 50 | 3 | 37.5 | 1 | 12.5 | 8 |
| 30-40 yrs. | 10 | 18.52 | 39 | 72.22 | 5 | 9.26 | 54 |
| > 40 yrs. | 2 | 25 | 6 | 75 | nil | - | 8 |
| Total | 16 |  | 48 |  | 6 |  |  |
| Gender |  |  |  |  |  |  |  |
| Father | 7 | 35.00 | 12 | 60.00 | 1 | 5.00 | 20 |
| Mother | 9 | 18.00 | 36 | 72.00 | 5 | 10.00 | 50 |
| Total | 16 |  | 48 |  | 6 |  |  |
| Occupation |  |  |  |  |  |  |  |
| Homemaker | 8 | 21.05 | 27 | 71.05 | 3 | 7.9 | 38 |
| Service | nil | - | 8 | 88.9 | 1 | 11.1 | 16 |
| Business | 2 | 40.00 | 3 | 60.00 | nil | - | 5 |
| others | 6 | 33.33 | 10 | 55.56 | 2 | 11.1 | 11 |
| Total | 16 |  | 48 |  | 6 |  |  |
| Family income Rs/month |  |  |  |  |  |  |  |
| ≤ 20000 |  |  |  |  |  |  |  |
| 20001-40000 | 6 | 70.00 | 3 | 30.00 | nil | - | 10 |
| >40000 | 3 | 5.4 | 32 | 86.49 | 2 | 8.11 | 37 |
| Total | 6 | 26.09 | 13 | 56.52 | 4 | 17.39 | 23 |
|  | 16 |  | 48 |  | 6 |  |  |
| Health related problem |  |  |  |  |  |  |  |
| Yes | 6 | 66.67 | 3 | 33.33 | nil | - | 9 |
| No | 10 | 16.39 | 45 | 73.77 | 6 | 9.84 | 61 |
| Total | 16 |  | 48 |  | 6 |  |  |
| How many hours do you spend for caring per week |  |  |  |  |  |  |  |
| ≤30 hrs |  |  |  |  |  |  |  |
| 31-60 hrs | 2 | 16.67 | 7 | 58.33 | 3 | 25.00 | 12 |
| > 60 hrs | 6 | 21.43 | 20 | 71.43 | 2 | 7.14 | 28 |
| Total | 8 | 26.67 | 21 | 70.00 | 1 | 3.33 | 30 |
|  | 16 |  | 48 |  | 6 |  |  |
| How long have you been a carer for |  |  |  |  |  |  |  |
| 0 to 3 | 7 | 15.22 | 34 | 73.91 | 5 | 10.87 | 46 |
| 4 to 6 | 6 | 33.33 | 11 | 61.11 | 1 | 5.56 | 18 |
| < 7 | 3 | 50.00 | 3 | 50.00 | nil | - | 6 |
| Total | 16 |  | 48 |  | 6 |  |  |

monthly family income and hours spent for caring by the parents per week (Table V).

**Table V: Chi square test of association between the quality of life of the parents with their Monthly family income and Hours spent for caring (n=70)**

| Demographic variables | Category | Below Median | At and above Median | Total | Chi square | P value |
|---|---|---|---|---|---|---|
| Monthly family income | ≤20000 | 9 | 1 | 10 | 7.46 | 0.023 |
| | 21000-40000 | 16 | 21 | 37 | | |
| | >40000 | 10 | 13 | 23 | | |
| | Total | 35 | 35 | 70 | | |
| How many hours do you spend for caring per week | ≤ 30 hrs | 3 | 9 | 12 | 9.08 | 0-010 |
| | 31-60 hrs | 11 | 17 | 28 | | |
| | > 60 hrs | 21 | 9 | 30 | | |
| | Total | 35 | 35 | 70 | | |

Chi-square df (2) 5.99, P <0.05

## DISCUSSION

The diagnosis of acute lymphoblastic leukemia in a child showed symptoms of depression and anxiety in parents which constitutes a major challenge hampering their quality of life (25, 26). Previous studies reported that parents of children with cancer had poorer QOL compared with parents with normal children or affected with other diseases (27).

The study was conducted with the core purposes of assessing the quality of life and its association with the selected demographic variables. The use of different Stem cell markers (like CD34) in the diagnosis of Leukemia has also been described by Bhattacharya & Poddar (28). Based on the objectives of the present study and its findings, a discussion was held in relation to other studies.

A study by Rosnah Sultan et al. on coping strategies among parents of children with acute lymphoblastic leukemia disseminated that half of the parents perceived their health-related quality of life as good. For parents the social relationship domain is highest and environmental health was the lowest (29).

With reference to the first question in the WHOQOL BREF scale (how would you rate your quality of life?), the results revealed that 149 (50.9%) of the parents perceived their quality of life as good and the second question (how satisfied are you with your health?), 151 (51.1%) of the parents reported that they were satisfied with their health. Regarding the domains of WHOQOL-BREF, the results showed that the quality of life to be poorest in the environment domain (mean 14.08±SD 2.09) and best in social relationship domain (mean 15.03±SD 2.68). Yet, not much difference was observed among the mean scores of the psychological and physical domains (29).

In the present study it was showed that majority of the parents perceived 'mid-range' quality of life and regarding the domain based on highest score, in the sense of value domain and lowest score in the ability to care domain.

Some limitations of this study includes that this study was limited to the parents of children with ALL in selected setting and was limited to the subjectivity of self reports by the parents regarding their quality of life. Besides, the population was relatively small restricting the generalization of the findings.

Recommendation for future study could take into consideration larger sample on a long term and periodic basis, to study quality of life at various points of management modalities and employing qualitative research. Future studies should also compare the quality of life among fathers and mothers and compare the quality of life of caregiver of children with ALL treated in public and private sector.

## CONCLUSION

From the study findings, it can be concluded that the maximum findings revealed that most of the parents of children with ALL experienced mid-range quality of life. It was also highlighted that there are few demographic characteristics which had impact on quality of life. During the conversation with the parents, it was evident that quality of life is an important factor for children diagnosed with ALL. The present study was conducted to assess the quality of life which is a quality indicator of the care offered and measure of treatment adherence of the clients. Therefore, these findings, has a definite role in nursing practices, nursing educations, nursing administration and nursing research.

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